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Contents

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Statement of Purpose:
AIDS Treatment News reports on experimental and standard treatments, especially those available now. We interview physicians, scientists, other health professionals, and persons with AIDS or HIV; we also collect information from meetings and conferences, medical journals, and computer databases. Long-term survivors have usually tried many different treatments, and found combinations that work for them. *AIDS Treatment News* does not recommend particular therapies, but seeks to increase the options available.

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Bangkok AIDS Conference May Be Largest Ever, July 11 to 16.....

The XV International AIDS Conference in Bangkok next month is expecting 15,000 attendees and may be the largest AIDS conference ever. Anyone can receive free daily email updates during the conference, and many other reports will be presented later. Unfortunately the Bush Administration told about 80% of the U.S. government scientists expecting to go that they will not be sent.

Ronald Reagan Remembered.....

Here is a transcript of the first public mention of AIDS in the Reagan White House, after 200 people had died.

New Medicare-Approved Prescription Drug Discount Card

by John S. James

June 9, 2004: The new Medicare-approved discount cards went into effect on June 1. They are the first step of a badly flawed but sometimes beneficial Medicare prescription-drug program, in which the U.S. government will spend hundreds of billions of dollars over the next ten years. Because of the huge amount of public money involved, eligible patients will need to deal with this program despite its problems. One big challenge will be the complexity of the process, and the difficulty of making the best decisions given one's medical needs and other circumstances.

This article outlines some basics about the program. Before making decisions always check for recent information, and get help from a benefits counselor or other well-informed adviser if possible.

Note that the Medicare "transitional assistance" discount prescription card recently in the news is a temporary program, which will last 19 months. Then, in January 2006, the discount card will be replaced by a more important but even more complex Medicare "Part D" drug benefit, which will require additional decisions by patients.

Who Is Eligible for the Medicare

Discount Card Now?

To be eligible for the new discount card you must be eligible for Medicare. And you must *not* be receiving outpatient prescription drugs through Medicaid or certain similar "Section 1115" programs. (Note: If you are "spending down" to become eligible for Medicaid, but are not on Medicaid yet, you *can* get the Medicare discount card. At least for now there is no look-back to take away the card if you later receive Medicaid.)

Those in Medicare who have non-Medicaid drug coverage, such as private insurance, are allowed to get a Medicare card (though usually not the $600 low-income credit -- see below). Those with good insurance or other coverage may not have much reason to, because traditional health insurance will almost always be better than the new Medicare card, which is intended mainly for those who have no other help and would otherwise be paying the full price for their prescriptions out of pocket. But some health insurance today, even from major companies, has such bad drug coverage that patients may need to buy many of their prescriptions out of pocket despite the insurance, so the Medicare card discounts might be useful. You can decide whether or not to use this card for any particular purchase.

Low-Income Benefit, $600 Per Year

The new Medicare card is most valuable for persons with a low income -- under 135% of the Federal poverty level, which currently means less than about $1048 monthly for one person (add $358 for each additional family member). We have heard that some income might not have to be counted, because Medicare normally follows the Social Security law, which specifically requires certain exemptions or disregards, especially for some earned income. It seems unlikely that Medicare will have the staff to adjust the income that applicants report, and we do not know if applicants can legally use these statutory exemptions or disregards to lower their income when applying for a Medicare-approved card.

Note: "You cannot get the low-income benefits if you already have drug coverage from your current or former employer, Medicaid, the Federal Employee Health Benefits Program, Tricare, or the Veterans Administration" (quoted from "76 Things You Should Know about the New Medicare Discount Cards," Center for Medicare Rights, http://www.medicarerights.org/).

Those who meet the income requirement will not only get whatever discounts the card offers (which apply regardless of income), but also will have their card programmed with $600 per year credit to buy prescription drugs; the Medicare card will work like a debit card, but for prescriptions only. This $600 credit can be used for almost any FDA-approved prescription drug -- even if the particular card does not list it and offer a discount. Also, for those who meet this income requirement, the Medicare card is free; for others, it will usually cost $30 per year (it may cost less, but cannot cost more).

Low-income patients might have to pay a 5% or 10% "co-insurance" fee when using the $600 credit (see Note#1, in the Notes section below).

In addition, some pharmaceutical companies will tie their "patient assistance program" (PAP) to the cards for those who meet the low-income requirement -- so that after they have used up their $600 credit they will get certain drugs free or at low cost from the manufacturer. This will apply only to some pharmaceutical companies, only to some of their drugs, and probably to only some of the 40+ different Medicare-approved discount cards now being offered. The importance of this benefit is increased by the fact that these programs often work poorly for individual patients -- and pharmaceutical companies will be under pressure to make them work better for a new, high-profile Federal program (especially before the November 2 election). For more information on coordination between the $600 low-income benefit and PAPs, see Note #2, below.

Many persons who are eligible for the Medicare card and the $600 low-income credit, but are in state pharmaceutical assistance programs (SPAPs) available in some states, or Medicare HMOs, will be signed up automatically for a card by their plan. They will not need to apply or do anything. We have heard that under the Medicare law, ADAPs (state AIDS Drug Assistance Programs) *cannot* sign up their clients automatically, because ADAPs do not meet the legal definition of an SPAP. This may be good news, as it turns out.

Who Gets the $600 Credit -- You or the State?

The annual $600 low-income prescription credit in the temporary Medicare card

system would seldom buy one month of antiretrovirals. If you are on ADAP, and also get the Medicare card with the $600 low-income credit, will your entire $600 benefit be used up the first time you purchase antiretrovirals with your ADAP card -- leaving you unable to use that money for prescriptions you need that are not on your ADAP's formulary, or for various emergencies? This is a complicated issue, and we do not have complete information yet.

Since state ADAP programs cannot automatically enroll their clients in a particular Medicare card, they may be unlikely to bill your Medicare card automatically when you get your ADAP prescription, largely because of the administrative difficulties of doing so. But it could happen that some state ADAP programs will automatically charge your Medicare account. We have also heard that under the new Federal law, the patient has control of the $600 prescription benefit, and can spend it on any FDA-approved prescription drug (there might be a few special exceptions), regardless of whether that drug is listed in any formulary. We do not know yet whether a state ADAP could demand that you use the money for ADAP prescriptions, or drop you from the ADAP program.

In some cases you may have to insist that the rushed clerk in the pharmacy does not use up your $600 without your consent. It might happen without your knowledge, all electronically with a swipe of your ADAP card. As of early June 2004, no one knows if this will be a problem, and if so, what patients may need to do to prevent it.

State ADAP programs can certainly use more money, so that they can reduce waiting lists and otherwise enable more people to receive HIV treatment. If you can save money for ADAP by using other prescription coverage, that will help. For example, veterans with an honorable or general discharge and income under about $30,000 per year can get prescriptions from the VA for $7 each.

But the $600 annual low-income Medicare benefit will most likely be needed for medically necessary non-ADAP prescriptions, or for emergencies. Keep in touch with the community and get advice, to make sure that this money is not wiped out by one month of antiretroviral coverage.

Note: the low-income patients in the standard state pharmaceutical assistance programs (SPAPs) who are automatically enrolled in a particular Medicare card by their state usually will have their $600 benefit charged for their state SPAP prescriptions, unless they can insist otherwise. This problem is less severe for them than it would be with ADAP, however. That is because most SPAPs cover all FDA-approved prescription drugs (with certain exceptions, such as cosmetics), so if the Medicare $600 is gone, the patient may still be able to get the prescriptions through SPAP. But ADAPs, even in the most generous states, do not even pretend to cover all medically necessary prescriptions -- only those on that state's ADAP formulary of drugs often used in HIV treatment. And this formulary varies immensely from state to state. If the Medicare $600 is used up immediately by ADAP, you may have to pay out of pocket for other prescriptions you need, or go without the drugs.

While ADAP is available in all U.S. states, SPAPs -- intended to help patients not quite poor enough for Medicaid buy prescription drugs -- are available in fewer than half of the states. The following states currently have SPAPs that can cover both aged and disabled: Connecticut, Delaware, Illinois, Maine, Maryland, Massachusetts, Minnesota, New Jersey, Vermont and Wyoming; all have open formularies except Illinois, which does not include any HIV drugs. Disabled persons in these states may want to see if they meet the requirements of these programs, especially for prescriptions that ADAP does not pay for. Twelve other states have SPAPs that only cover aged (usually 65 and over, but age 50 and over in Rhode Island), and do not include disabled persons under that age. The rest of the states do not provide this pharmaceutical benefit to anybody.

AIDS organizations will need to do more to understand prescription drug pricing, benefits programs, and how both work in practice -- and make sure this information gets to patients who need it. Patients must learn how to save themselves when possible, in a fragmented healthcare system designed mainly to benefit corporations.

Choosing a Medicare-Approved Prescription Drug Discount Card

About 40 national cards and about 30 regional cards are currently offered by

various businesses, and by some nonprofit organizations. Most of the publicity about the difficulty of the choosing a card concerns finding the best discount. We suspect that for people with HIV, the coordination with other programs may become the more important and more difficult choice -- especially for those eligible for the $600 low-income prescription-drug credit in 2004 and 2005. (Toward the end of 2005 patients will have to make new decisions for the more complex but more valuable Medicare Part D that starts in January 2006.)

Here are some points to keep in mind:

1. The card is entirely optional. And since most of the discounts it offers are not very impressive compared to good mail-order pharmacies, persons in Medicare who do *not* meet the low-income requirement noted above may choose not to bother. For those who *do* meet the low-income level, the card is more important because it will provide $600 this year and $600 next year for prescription drugs (in addition to any advantages in getting free or low-cost drugs under PAPs, as mentioned above).

2. To see if the discounts are important to you, compare the prices on the official Medicare site (http://www.medicare.gov -- you can check prices without signing up) with the prices anyone can get through an Internet pharmacy such as http://www.drugstore.com or http://www.costco.com (click "pharmacy"). Be aware that the Medicare site has had many errors.

Discounts through the Medicare cards are likely to be better for generics than for patent-monopoly drugs.

You could also check http://www.canadadrugs.com to compare Canadian prices. (Note the huge difference for Norvir after Abbott's 400% U.S. price increase on December 3, 2003.)

Experts agree that patients need Internet access to effectively compare the different discounts and choose a Medicare card. (However, on June 3, 2004, the Kaiser Family Foundation released "results from a new Kaiser survey showing that 31% of seniors have ever used the Internet, with a vast digital divide. Only 15% of seniors with incomes below $20,000 say they have ever gone online.")

3. Before choosing a card, make sure it is accepted by the pharmacy or pharmacies you use.

4. If you do get the card, you do not need to use it for any particular purchase; so if you have other drug discounts, you can use whichever is best. One problem that may arise, however, is that pharmacies may be reluctant to swipe various cards to see which gives you the best discount, because they are probably charged for each swipe. And if you give the clerk both your ADAP and Medicare cards, that might increase the risk of your $600 Medicare benefit being used without your knowledge.

5. There is no rush to sign up for the Medicare card right away, as usually the only penalty for waiting is that you lose the discount for drugs you purchase in the meantime. However, it is important that those who meet the low-income requirement for the $600 credit sign up in 2004, since otherwise this year's $600 will be lost. Money left over in 2004 can be carried over to 2005.

We do not know the exact deadline for eligible patients to start the process of signing up for the Medicare card and $600 credit in 2004, but would consider doing so before November 2. The Medicare drug benefit is a highly political program, with huge institutional incentives to make it look good before the election, and hide problems until afterwards.

6. Once you choose a Medicare prescription drug discount card, you are locked into that card for the calendar year (in 2004, you can change cards starting November 15). However, the card can change what discounts it offers every week -- the new discounts appear on the Medicare Web site on Monday -- so the discount(s) you need may go away, and still you are stuck with that card. We have never seen an explanation of how one is expected to make a rational choice of cards under this condition.

In practice this problem might be less than it seems. This is because the major reason companies are offering the cards is not to pick up resulting drug sales, but to position themselves to get a chunk of the big money that will start to flow after the cards are replaced by the new Medicare Part D drug benefit in January 2006. So these companies would be well advised not to pull major surprises by attracting business with big discounts that then go away, after the customer is locked in under this new Federal program. The bad publicity could easily cost them more after 2006 than any profit they might gain now.

7. Unfortunately at least one pharmaceutical company may end its patient assistance program, and replace it by one that uses its own Medicare card. This would deny assistance to those not on Medicare even though they had no possible way to pay for the drug, and force those on Medicare to use the company's Medicare card if they need that company's drugs through a patient assistance program. According to a June 4 alert from the Medicare Rights Center -- http://www.medicarerights.org/ -- Pfizer has plans to end its Share Card on August 31, 2004, affecting more than 560,000 people.

8. Eligible persons can start the enrollment process at http://www.medicare.gov, by calling 1-800-MEDICARE, or by answering the advertisements some patients have received. It might be best to compare various discounts now, but then wait for the situation to clarify before choosing a card and being locked in to it. One way to simplify the discount shopping would be to focus on the one, two, or three drugs where a price reduction would be most important for you. However, the Medicare site has software that lets you enter a larger number of drugs and get a total price.

For background information on applying for a card, see http://www.medicarerights.org/.

Medicare "Part D" Drug Benefit, Starting January 2006

This new drug benefit will replace the Medicare cards in January 2006. HIV benefits expert Tom McCormack told us about two good things in this program:

"Above all, the income level for getting free or nearly free drug coverage if you are on Medicare and are poor will be raised to 150% of poverty ($1164 monthly for one in today's 2004 dollars; add $398 for each additional family member) beginning in 2006. In contrast, present Medicaid income levels that determine which poor Medicare patients get nearly free drugs are about $564 (or a little more) in about 30 states and about $776 (or a little more) in about 20 states. So the new Medicare drug law makes an enormous liberalization in the income level for drug coverage of the poor.

"Also, while formularies (restricted lists of drugs that Medicare drug plans will cover) are allowed by the law, we do know so far that at least one Medicare drug plan---the AARP-sponsored United plan, which is member- and consumer-run and has for years served AARP members well, has 59,000 participating drug stores, a mail-order service and a good price discount record --- will offer an *open* formulary and will cover *all* FDA-approved drugs. Medicare patients need *not* be AARP members or over age 50 to join this drug plan. As we learn of any other open formulary Medicare drug plans, we will share that news."

HIV Summary

The $600 annual low-income benefit of the new card could seldom pay for even one month of antiretroviral treatment. But if one does not need antiretrovirals, or has ADAP or other coverage for them, the $600 can help with other prescriptions. Patients in some states with the $600 benefit *might* need to make sure that this benefit is not used up immediately by being charged for major ADAP purchases without their knowledge and consent. Watch for more information as it becomes available.

The card's discounts are unlikely to be large for antiretrovirals, unless manufacturers decide to create a special low price for persons on Medicare with these cards. This is because all the antiretrovirals are patented drugs in the U.S., so the patent holder can set whatever price it wants, and does not need to offer discounts. And other costs for distribution, pharmacy, etc. are small in comparison, so there are no significant savings to be gained.

Starting in January 2006, a new Medicare Part D drug benefit will replace the discount card and the $600 low-income benefit. It may offer important help to those with an income less than 150% of Federal poverty level (and to those with higher incomes, but they will have much higher co-payments). Advising clients will become even more difficult than with the Medicare card, and much more critical; clients will need to start making these decisions a little over a year from now. Better coordination of medical programs will become more important, and could become a major activist issue.

Comment: Why Is the Medicare Discount Card Designed As It Is?

The entire Medicare prescription-drug program was created in a hurry by Republicans in Congress to help their party in the November 2, 2004 elections. Democrats, who have always taken the lead

on this issue, were almost entirely shut out from having input into what the program looks like. The result is what we now have to live with.

[Note: Democrats did get two changes in the Conference Committee, the final stage of Federal legislation. These changes apply starting January 2006, to the new Medicare part D drug benefit -- not to the current Medicare-approved card. Co-payments for the poorest Medicare patients will be on a sliding scale, starting as low as $1 per generic prescription; the Republicans would have made this 15% of the drug's retail price. Also due to the work of Democrats on the Conference Committee and their staffs, the income level to qualify for coverage without the "donut hole" (that after some initial prescription coverage, will require $3,600 out-of-pocket prescription expenses in case of major illness before the new Medicare Part D 95% "catastrophic" coverage begins), was raised from 135% of Federal poverty to 150%.]

The Medicare card system is complex because it was designed to demonstrate an ideological point -- that "free enterprise" makes government action unnecessary to assure that people can afford critically needed drugs. The idea is that the different card-offering companies and organizations will have an incentive to offer big discounts in order to get more enrollees -- giving them numbers which they can then take to the pharmaceutical companies to negotiate bigger discounts, getting them more enrollees, etc.

This may work to some extent for generic drugs, where huge markups remain in the U.S. market for no clear reason. And it may also reduce markups at some retail pharmacies, since the price for each drug with each card is published. But the major problem is with patent-monopoly drugs, where far larger markups exist because prices are set at what the rich market will bear -- and politicians are well paid to put the interests of industry first, and abandon the elderly, disabled, and poor if necessary. Drug distribution through Internet pharmacies is already efficient, so there is little savings to be found there.

And why are people locked into the cards except once a year, while the issuing companies can change what they offer every week -- making it impossible for individuals to make rational decisions? This follows from what we call fake free enterprise -- pretending to have free markets in a world really dominated by large institutions. What happens is that the free-enterprise rules get applied selectively to serve the interests of major institutions and powerful insiders.

If patients were allowed to change cards at will, many would find it in their interest to change with every purchase. Allowing individuals to have frequent changes or multiple cards would complicate the system and could increase the risk of fraud. But the card issuers must be allowed to change their benefits frequently, in order to create an ongoing market. The bottom line in this case (as in so many others) is that at the end of the day, powerful institutions get what they need, and people don't.

A separate problem postponed until after the November 2 election is that the Medicare Part B premium is expected to go up from $66.60 to an estimated $78.10 next year, because the new law increases the payment for doctors, hospitals, and HMOs, before the government starts paying for the Medicare Part D benefit in 2006. But persons on Medicare with income under 135% of Federal poverty level (after subtracting $20 of any income, and $65 and half the rest of any wages), and meeting asset requirements, can already get the Part B premium paid for them, through QMB (Qualified Medicare Beneficiary), SLIMB (Specified Low-Income Medicare Beneficiary), or QI (Qualified Individual). People must apply for this support through state welfare (not federal Medicare) offices, and many do not know about these programs.

The bottom line on the new Medicare law is that it was designed to help large corporations, and will do that very well; almost all the money spent in this program goes to them. It will also help people, but hit-or-miss, with great cost and complexity.

The long-term problem is that U.S. society is becoming a corporate/government feudalism, where huge institutions take care of themselves and each other, but ignore peoples' needs when convenient. If Americans die because they cannot afford essential medicines, it is cheaper to stonewall them, and perhaps fill the media with heartwarming PR, than to fix the problems. This abusive style, now common in U.S. corporate and government operations, degrades the quality of life of almost everyone in the country. It will continue until

more people stop believing disinformation, take back control of their future, and insist on institutional as well as personal responsibility.

Notes:

HIV benefits expert Tom McCormack sent us the following information about the Medicare prescription-drug discount card, on May 31, 2004. He is speaking here as an individual and not as a member of any organization:

1. "Patients with incomes under 100% Federal Poverty Level ($776 monthly for one; add $265 for each additional family member) get charged a 5%-of-retail-price co-insurance while using their $600 allowance to buy prescriptions; those with incomes from 100% to 135% get charged a 10% co-insurance. But this co-insurance can be waived individually by drug stores if patients can't or won't pay it, as long as the drug store does not do so routinely for everyone or advertise such waivers."

Apparently the pharmacy is not required to waive the fee if asked, however. And under Medicare part D, which starts in January 2006, pharmacies will not be allowed to waive fees even if they want to.

2. "The drug makers listed at
http://www.cms.hhs.gov/medicarereform/drugcard/mfragreements.asp
on the CMS Medicare website have agreements with the indicated Medicare $600 Transitional Assistance drug discount card sponsors. They'll qualify such TA (Medicare) card members, once their $600 allowances are used up, for whatever manufacturer Patient Assistance Program (PAP) that manufacturer offers---supposedly (we hope) without the need to complete any additional paperwork or undergo further processing. (Note on the chart the crucial fact that, so far, the AARP/United plan also has agreements with almost all interim TA $600 card sponsors for its low-income customers to access company PAPs once their $600 allowances are used up.)"

Notice: *AIDS Treatment News* wrote this article during the first week of the new Medicare program -- before anyone knows how it will really work in practice. Always check for recent information and advice. One place to look is http://www.medicarerights.org/ -- but check on AIDS sites as well. Our community must work together on benefits education, to help people receive essential medical care.

Institute of Medicine Urges Restructuring of U.S. Low-Income HIV Treatment and Care

by John S. James

A Congressionally mandated study sponsored by the U.S. Department of Health and Human Services has urged that the U.S. replace the current patchwork of Medicaid and other funding mechanisms with an HIV Comprehensive Care Program having "a strong focus on comprehensive and continuous primary care, substance abuse, and mental health services to support adherence to HAART." The proposed program, a Federally funded entitlement administered by the states and meeting nationwide standards of treatment and of provider reimbursement at the Medicare (not Medicaid) rate, would be open to families up to 250% of Federal poverty level, but those with higher incomes and without access to private insurance could join on a sliding scale. The committee of 16 experts who produced the report estimated that this system would increase Federal spending $5.6 billion over 10 years, and prevent 20,000 deaths during that time. Thousands now go without treatment due to lack of funding, uncoordinated eligibility requirements, and other problems.

The program would cost $4.2 billion less over the 10 years, however, if the government paid the same discounted prices for antiretrovirals as it currently pays for the Veterans Administration and some other Federal agencies.

"Failing to provide these cost-effective, life-saving drugs to all Americans who need them -- including individuals who lack insurance or cannot afford them -- is indefensible," said the committee chair, Lauren LeRoy, president and CEO of Grantmakers in Health, Washington, D.C.

The Institute of Medicine announced the report on May 13, although only pre-publication copies were then available.

Note: "entitlement" programs are those that provide coverage to all who qualify, instead of depending on annual appropriations. Medicare and Medicaid are entitlements; ADAP is not. This is why no one has to stop seeing their Medicare doctor a